

Experiences of Parents Assisting their Children Diagnosed with Autism Spectrum Disorder in Regular Education Classes

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Abstract:

One in every 100 Filipinos has autism spectrum disorder (ASD), a condition that impacts one's social interaction, education, communication, and behavior. There have been numerous studies showing the prevalence of ASD among children, as well as the experiences of their parents in assisting them in integrated Special Education (SPED) school programs. However, fewer studies researched the experiences of parents whose children are in regular classes. Consequently, this study aims to investigate the experiences of parents assisting their children, aged eight to twelve, diagnosed with ASD in regular classes through a phenomenological approach. However, the study only has a small sample size of three participants with children of different ages: eight, ten, and eleven. It may not be enough to generalize the population. Data was gathered through snowball sampling and one-time interviews, focusing on their experiences, such as satisfaction, challenges, coping mechanisms, and parenting strategies in assisting their children with ASD in taking lower primary regular classes. Using the Stress Process Theory, the interview deduced three prime themes: Challenging Experiences, Resiliency of Parents, and Sense of Fulfillment. The study concluded that some of the challenges the parents face are the lack of prepared inclusive education and societal judgment. However, despite many challenges, parents found the experience rewarding, especially seeing their children's development. Furthermore, excerpts show that parents are devoted to helping the development of their children. Thus, the researchers recommend the refinement of mainstream education to accommodate those with developmental needs.

Key Words: Autism Spectrum Disorder; Parent's Experiences; Children's Education; Mainstream Education

1. INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects an individual's ability to interact, learn, communicate, and behave (Hyman, 2020). A study from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (2017) revealed that behavioral symptoms of ASD often show up early in development, wherein many children exhibit symptoms of autism as early as 12 to 18 months old. Statistics showed that the Philippines had an autism rate of 81.80 prevalence per 10,000 children (World Population Review, 2023).

To address this, policies were implemented to assist people with ASD in the Philippines. The Republic Act - 7277: Magna Carta for Disabled People, which protects people with extra needs, and strengthened the development of Special Education (SPED) programs in the country (APEID, 2001). SPED programs aim to help learners with additional needs reach their full potential and be self-sufficient citizens in the future (Allam, 2021).

Meanwhile, in assisting their children who are learners in SPED programs, parents experience several demanding challenges (Estojero et al., 2022). To elaborate, parents go through a spectrum of emotions, including anxiety, rage, guilt, acceptance, and hope, as

they grasp their child's condition. The following emotions have shown a drastic increase as parents experience stress. Furthermore, according to both Tshabalala (2011) and Okeke & Mazibuko (2014), some parents may not understand the diagnosis due to a lack of preparedness and education regarding the situation and may not be able to assist their children at all despite wanting to. However, a study by Mipanga (2022) revealed that parents of SPED learners feel relieved and reassured about dedicating parental support after generally painfully adjusting to their child's needs.

Consequently, many studies have shown the prevalence of children with ASD and their parents' experiences assisting them in integrated SPED schools. However, some children with ASD are accommodated into the regular educational system, hoping to perform at a higher level (Hemann, 2007). The regular educational system differs from SPED programs as SPED schools focus on a holistic approach in education, seeing collaboration of parents and school personnel as crucial. However, in regular education, each student is held accountable for their own progress, with teachers and parents as secondary personnel that only guides students (Oyola, 2016). As a result, students with ASD experience less guidance, which adds to the demanding challenges parents experience.

Thus, this study aims to investigate the experiences parents face in assisting their children, aged eight to twelve, diagnosed with ASD. Specifically, identify the situations parents face, their satisfactions, challenges, coping mechanisms, and parenting strategies when assisting their children diagnosed with ASD in mainstream settings.

2. METHODOLOGY

2.1 Research Design

A phenomenological approach was used in the study to explore the experiences of parents assisting their children diagnosed with ASD in regular education classes. Phenomenological studies aim to examine a phenomenon's essence by exploring the viewpoints of those experiencing it (Neubauer et al., 2019). The interview questions in this paper revolved around investigating the experiences of parents and elements that influenced the experiences of the phenomenon. Additionally, open-ended questions were utilized during the interviews as it is one of the techniques in phenomenological studies. It aims to draw broad

conclusions about the way a phenomenon is experienced. Therefore, the phenomenological approach is the most appropriate research strategy for the study.

2.2 Sampling Procedure

The researchers used the snowball sampling method to select the three participants needed for the study. Snowball sampling is a non-probability method where other participants recruit new participants to form part of the sample. This sampling method encourages participants from hidden populations, including those relating to sensitive topics (Dosek, 2021). However, sampling and under-coverage bias emerge from this type of sampling, as it has a small sample size and relies on referrals (Parker et al., 2019). Furthermore, researchers only choose parents with children aged eight to twelve as it is associated with increased emotional and social changes, which can add to the difficulties parents face (Breehl and Caban, 2022).

Initially, the researchers contacted three parents. Afterward, the researchers requested them to refer the study to other parents who may share the same experience, which brought three other parents in line with the objective: to gather the experiences of parents assisting their children diagnosed with ASD in regular education classes.

2.3 Validation of Instruments

The researchers ensured a clear and concise interview questionnaire so that the respondents understood the inquiries about their experiences (Jain, 2016). Furthermore, the researchers submitted the interview questionnaires to their research adviser and two other research teachers for validation. Revisions were made based on the feedback of the validators.

2.4 Ethical Considerations

The participation of parents was entirely voluntary (Mustajoki and Mustajoki, 2017). The researchers first sent the survey forms to parents with children diagnosed with ASD through Google Forms. In the survey, the researchers asked for the respondents' consent under the Data Privacy Act of 2012 (RA10173). Furthermore, the researchers ensured that their data was only used for research purposes and kept with utmost confidentiality. At the end of the survey, the respondents were given the option to proceed with the

interview at their preferred schedule. Moreover, consent forms were given before the interview. Code names were also given to the parents and their children. In addition, confidentiality of the information is maintained by limiting access to only the researchers (Mustajoki and Mustajoki, 2017).

2.5 Data Gathering Procedures

The study utilized Google Forms for the pre-interview survey. Then, the researchers contacted the chosen respondents to schedule a one-time online interview. Before the interview, the participants signed a consent form wherein they were informed about the data collection procedures and agreed to take part in the interview proper (Mustajoki and Mustajoki, 2017).

Then, the researchers interviewed at the agreed time and date. Before recording each interview, researchers informed the respondents. In addition, data was managed by reviewing notes and recordings for transcription and thorough assessment (Mustajoki and Mustajoki, 2017). Similar answers are also grouped for the identification of patterns. Moreover, any misinformation that could jeopardize the validity of the data was excluded (Braun and Clarke, 2013).

2.6 Methods of Data Analysis

Data was analyzed using Thematic Network Analysis by Clarke and Braun (2013) and Stress Process Theory as the Thematic Framework by Pearlin et al. (1981). Analyzation texts, such as interviews, were done qualitatively using thematic analysis. The researchers carefully examined the data to find significant patterns, concepts, and themes that emerge repeatedly.

The data collected through interviews were transcribed, and distinct code names were assigned to each participant to safeguard their privacy and ensure the confidentiality of their personal information. The researchers developed analysis by deriving insights from the identified themes and associated data. This analysis was articulated by narrating the data in alignment with the research questions.

3. RESULTS AND DISCUSSION

The purpose of this study is to investigate the experiences of parents when assisting their eight to twelve-year-old children diagnosed with ASD in attending regular classes. The collected responses were

carefully analyzed and categorized to develop themes. Variables such as the parents' kinds of satisfaction, challenges, coping mechanisms, and strategies for assisting their children were also taken into account when exploring their overall experiences.

3.1 Challenging Experiences of Parents

Parents of children diagnosed with ASD experience a multitude of challenges due to societal barriers. The main factor for their academic hardships is insufficient inclusive education. According to the interviewees, they experienced frequent moving and rejection of their children due to the schools' lack of preparedness. Furthermore, they experience an underlying stigma that limits their access to quality education as seen in Table 1, excerpts of P2/A2 and P3/A1. In line with the study of Estojero et al. (2022), parents experience the same narrative of discrimination within society. "Because other people bully him and would call him mongoloid," an excerpt from Estojero et al. (2022) study further verifies their universal experience.

In addition, people with ASD, especially children, face challenges in expressing themselves and understanding others (Hyman, 2020). Due to this, parents struggle to communicate with their children. Kids diagnosed with ASD may exhibit intense, specialized interests or repeating behaviors, which may restrict their capacity for reciprocal dialogue. Furthermore, ASD-related communication challenges might result in misinterpretations.

Lastly, parents also experience stress due to the uncertainty of societal perceptions and the future progress of their children. The lack of predictability raises parents' concerns and in turn, adds additional stress, as expressed by the interviewees.

Table 1. Excerpts of Challenging Experiences of Parents

Respondent	Quotations
P1/A1	"She still has a bit of behavior that isn't really tantrums but it's just that their behavior is really different when it comes to their parents..."
P2/A1	"...we became school hoppers because we wanted to find the best school for him..."

P3/A1	"There was one school, I didn't even explain yet. Already said no."
P3/A2	"It was filled with nervousness and fear. The worry of "What happens next?" will never go away..."

Table Legend: P, Participant; A, Answer

3.2 Satisfaction and Sense of Fulfillment

Parents continuously provide adequate care to their children throughout all the challenges. They can improve the emotional connection they have with their children. Due to their children being diagnosed with ASD, they develop social skills such as communication, which were previously challenging to reinforce. Over time, these skills enhance, leading to a stronger bond between the parents and children. Additionally, they can respond to their child's needs, which satisfies not only the parents but also their relatives.

In addition, supportive environments help lessen parents' stress and give more insights into parenting, which can improve both the child's and the parent's well-being. Moreover, they also promote mainstreaming, which lessens the existing stigma. It is evident in one of the interviewee's responses (Table 2. P1/A1) and excerpts from the study of Mipanga (2022), such as, "I ask her younger sister to teach her. We should make sure that their siblings understand their situation and would care as we are taking care of them."

Lastly, seeing their children's improvements brings them a sense of fulfillment and joy because they accept their situation, which enables them to respond accordingly.

Table 2. Excerpts of Satisfying Experiences of Parents

Respondent	Quotations
P1/A1	"...thoughts get offset if you see their improvement. Even our relatives are happy to see her..."
P2/A1	"...he's done a lot to make us happy. Things that a typical child won't be able to do in order to make their parents happy..."
P3/A1	"So, when I see that he can do it, that's where the feeling of fulfillment comes..."

Table Legend: P, Participant; A, Answer

3.3 Resiliency of Parents

Parents are striving to provide their children with competent protection and care. They assess their position and mental state before they provide adequate guidance and care. Acceptance and having a secure mindset develop parents' strengths and enable them to make suitable decisions for their children's education. Parents experiencing challenges in assisting their children with ASD start to cope by adapting to their situations and building resilience. Emphasized by an excerpt from the study of Estojero et al. (2022), "I just take the responsibility though it is so hard and expensive", which is similar to the sentiment of P1/A1 in Table 3.

Adaptations and resiliency can take the form of many types of educational help, such as SPED Schooling, Parent-Institute Collaborations, Shadow Mentoring, tutoring, and therapy. By understanding the societal barriers affecting their children, parents can decide which type is necessary to apply for them. As parents are able to provide proper support for their children with ASD, they are able to succeed in overcoming hurdles. These achievements serve as a means of coping by replacing their unpleasant emotions with motivation, therefore enhancing their resilience.

Table 3. Excerpts of the Resiliency of Parents

Respondent	Quotations
P1/A1	"To be honest, it's really challenging but there will be a time where you need to accept it... it's really the key to overcoming hardships..."
P2/A1	"So we pay a lot for his learning and, at the same time, his shadow mentor."
P3/A1	"Actually, in terms of entering mainstream education, I would describe it as challenging but very fulfilling... That's why we have learned to take one day at a time."

Table Legend: P, Participant; A, Answer

3.4 Parenting Strategies

Parents invest significant efforts in navigating various educational options to ensure the best learning environment for their children with ASD. They prioritize mainstream schools and supplementary therapies to

enhance cognitive development and academic skills. Furthermore, parents also engage in extensive research, consult with professionals, and actively seek diverse educational resources to align with their child's needs.

Furthermore, parents of children diagnosed with ASD actively create a supportive learning environment, addressing academic and emotional needs while establishing routines, and adaptability to enhance their children's educational experiences and overall development. Parents also recognize the needs of their children and adapt their parenting styles accordingly (Mipanga, 2022).

Lastly, parents are actively involved in various aspects of their child's educational journey, participating in school activities and fostering collaborative learning with professionals and peers (Estojero et al., 2022). Parents participate in extracurricular activities, parent-teacher conferences, and even administrative roles.

This proactive stance extends beyond academics, encompassing the child's overall development. Thus, parents maintain open communication between educators and experts to address concerns, collaborate on goal-setting, and advocate for their child's needs within the educational settings.

4. CONCLUSION

The study aimed to investigate and evaluate the experiences and situations of parents when assisting their children, aged eight to twelve, diagnosed with ASD, attending regular education classes. The researchers analyzed interviews and past data to uncover the parents' challenges, coping mechanisms, and strategies. Findings emphasized parental satisfaction with children's progress and fulfillment in assisting them in their education.

Parents expressed satisfaction in witnessing their children's improvement and development, alongside a sense of accomplishment in supporting them. However, challenges included managing behavior, communication difficulties, and societal stigma. Moreover, adjusting expectations and prioritizing coping strategies helped parents overcome these challenges.

Despite the complexities, parents found the

experience rewarding. They devoted significant time and energy to researching, consulting professionals, and creating a supportive learning environment for their children. In addition, collaborative approaches and adaptive parenting styles were crucial. Furthermore, it is important to remember that the stories of families with children with ASD go beyond the scope of this study and additional research is needed to thoroughly understand their experiences.

The researchers suggest schools that intend to enhance education for children diagnosed with ASD should utilize this study to evaluate parental experiences with the school system and conduct a similar study to obtain a broader perspective on this issue. Lastly, the researchers recommend refining the educational system to accommodate those with developmental disabilities, ensuring equitable treatment given to learners with special needs, and aligning with DepEd Order No. 44 Series 2021.

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